

November 9, 1986

Dear Don,

Was most delighted to receive your letter yesterday. Thanks so much for taking the time out to bring me up to date with what is going on in your life. The programs that you sent are beautifully done. If the productions that they represent were as well produced, I'm sure they were stunning affairs. Hope you met your financial goals. America's Finest City Freedom Band could use some of your talent and professional skills.

Friday, November 7th, I went up to Los Angeles to hear Morris Kight and Don Kilhefner "Speak The Vision" (program enclosed). It was a wonderful evening. I wish you could have been there. I made an audio tape of the event, and, with any luck at all, I'll soon make a copy of it and send it off to you. I know you will enjoy it as much as I. It is full of "Morris-isms".

Don, I feel very strongly that the Brian Barlow case is a very important one and worth supporting. I feel very embarrassed that the incident even occurred in San Diego--especially to a San Franciscan who had come here specifically to support us on our Gay Pride Day. I will ask around to see if there is any energy to do some fund raising for the BBDF. But I am quite unable to provide any leadership for such an effort at the present. This town is more benefit-poor than usual in the wake of the "No on Proposition 64" campaign. And personally, I am feeling overwhelmed with my current level of activities with the San Diego AIDS Project. It's not that I am doing so much, but rather that I don't have the stamina that I once had. And with some very serious questions about my own health, (borderline ARC) I can not afford to exhaust myself like I used to.

1986 has been a year of great upheaval and turmoil for me personally. It began on December 31, 1985 with admission to the hospital with low back strain which I'm sure was secondary to the 3 days of non-stop coughing brought on by bronchitis that preceeded the back problem. I was hospitalized for 5 days in pelvic traction and then recuperated at home for 2 more weeks. During that time the bronchitis and sinusitis raged on unresponsive to various antibiotics until I placed myself on Isoprinosine (1 gram 3 times a day). After 2 weeks of that my symptoms began to clear. A similar thing had happened in the fall of '84 when, after 4 months of bronchitis (minimally responsive to 6 courses of antibiotics) I got well after 2 weeks on isoprinosine--ominous clues about the state of my immune system.

Anyhow, before the month of January was over, all my clothing, a few rugs, towels, bed sheets, and some curtains were stolen out of the washing machine at the local Launderland; through the magic of ATM's the bank lost a deposit of over \$600 causing checks to bounce all over the country; my typewriter, steam iron, alarm clock, and camera broke down simultaneously--all requiring replacement except the camera which was repaired for only \$94; and on January 31st I had an auto accident. It was a minor rear-ender with no injuries, but after the insurance company paid for the replacement of the rear gate I had to have the whole car repainted to make it match. My cost--just \$1100. I wasn't ready! It went on the mastercard which was already overloaded with the cost of replacing items lost in the theft. So I've spent the rest of this year trying to bring that balance down.

While all of this was going on, things were turning to shit at work. I

had been basically unhappy in my job for about a year and kept hoping that things would change or get better. Well, they changed but didn't get better. To make a long story short, I'll just say that I made a very painful decision that it was time for me to leave the Emergency Department. From the time that I made that decision until I actually found another position in the hospital it was nearly four months. Those four months were terribly depressing and demoralizing. There were a lot of unpleasanties between me and the head nurse, and I felt that I was treated very shabbily. I was angry and in a foul mood most of that time and not any fun to be around.

My difficulty with finding a position elsewhere in the hospital that was acceptable to me was also crushing to my ego. I felt that after 17 years at Scripps, constantly upgrading my skills, getting my RN in 1984, my bachelor's degree in 1985, I was more highly trained, experience and educated than ever, and the message that I was getting was that we just don't want you anymore. Under ordinary circumstances, I'd have told them to take the job and stick it. But my health was in such a severe state of decline that I was afraid to do anything that might jeopardize my health insurance or retirement plan.

You see, Don, by February I had developed chronic herpes, first either oropharyngeal or buttocks, then both places simultaneously. I was already on an isoprinosine/ribavirin regimen. To that we added oral acyclovir. Together with the megavitamins that raised my monthly drug bill to \$200--very little of which was covered by insurance. Further, there were monthly doctor visits with monthly lab tests. My hemoglobin & hematocrit began a downward spiral and my T-cell ratio went from 0.65 to 0.43 in 5 months. I began to feel like I was going to pass out after running up a flight of stairs and people began to comment on my paleness.

The herpes became so severe that it was very difficult to eat and I lost a little weight because of that. I remembered your friend who was hospitalized with a feeding tube in place due to oral herpes when I was in San Francisco in November 1985. I kept thinking that that was the next step for me. To try to prevent that, I went on intravenous acyclovir therapy for a week. I wasn't hospitalized, but rather kept working and administered my own IV medication by way of a hepain lock which I had placed in my upper arm by a very supportive nurse friend. I wore long sleeves to cover the hep-lock and kept the whole thing a secret from everyone who didn't absolutely have to know.

After 2 days of therapy, I had very dramatic improvement. But, alas, by the 4th day things were worse. We discontinued therapy on the 7th day, at a cost of \$90 a day, with nothing having been gained but the knowledge that acyclovir by any route was not the answer. My insurance paid 80%.

In addition to being depressed, angry, in pain, and plagued with financial woes, the herpes thing was really beginning to bother me because I knew that chronic herpes is one of the opportunistic infections that qualifies one for an AIDS diagnosis. At the time I thought that the definition of "chronic" (according to the CDC) was continuous for 3 months or more. I had been keeping this to myself as I neared the end of the 3rd month of non-stop herpes. Finally, I brought it up to my doctor along with the official three-page definition of AIDS from the CDC. As you may already know, I was wrong--the CDC defines chronic herpes as lasting for more than one month, not three. So by that criteria I had qualified for an AIDS diagnosis the first week of March. Shit!

My doctor admitted that "technically" I met the criteria for diagnosis, but that he felt uncomfortable making the diagnosis in the absence of any other opportunistic infection, persistent generalized lymphadenopathy, etc. After discussing my case with an infectious disease specialist, he said that they had to conclude that I do meet the official criteria for diagnosis but that they were not convinced enough to report it as a full-blow AIDS case. He stated that it would be a lot easier to get my name on a list of PWA's than to remove it at a later time if we felt that we had made a mistake, and that if I truly have AIDS it will show itself in an unmistakable way soon enough. How's that for a definite maybe?

Also during this same period, the cost of ribavirin went from \$80/month to \$240/month. I simply did not have that much money after all the other expense already mentioned. Clearly, it wasn't doing me any good, so I said "To hell with it all" and stopped taking the ribavirin, isoprinosine, and the acyclovir all at once. In 2 weeks the herpes were gone, my color and strength had returned and my CBC was completely normal for the first time in over a year. Well hooray! But who knows why? My doctor thinks that the medicine was making me sick.

The psychological impact of all this has been enormous, varied, and complex. As I began to share some of this information with a few selected friends I got the shock of my life. I found that most people are simply not equipped or are unwilling to deal with the subject. They either changed the subject, trivialized the matter or became emotional. In any event, a social distance developed that has taught me to keep my damned mouth shut regarding my health. No matter how lousy I might feel, I don't express it verbally. If asked outright, I just say "fine".

I am deeply hurt, angry, and my trust in fellow humans has been deeply eroded. I have responded by further isolating myself socially as a protection against further hurt and disappointment. I have been a giver most of my life and I naively assumed that at my time of crisis someone would be there to hold me when I needed to cry and feel sorry for myself. It didn't happen.

Meanwhile I had been given a deadline of July 1st to be out of the Emergency Department and 4 months of searching had produced no acceptable job. I was rejected by the Endoscopy Center, The Surgical Center for Ambulatory Treatment, the OR, Utilization Review, and even a medical/surgical floor. When I worked my last scheduled shift in the ER on June 28th I still had no job and so took a month's vacation. On July 22nd I accepted a temporary (3 month) full-time position in Quality Assurance to help the hospital prepare for the Joint Commission for the Accreditation of Hospitals (JCAH) inspection scheduled for mid September.

Having a temporary job didn't relieve my insecurities very much but it seemed distinctly better than no job and it did give me 3 months breathing space to think things over, 3 months more for something else to become available. There was also the added advantage of learning a new job and finding out whether I'd be happy doing anything other than patient care. I decided to learn as much as I could and become as valuable as possible in three months, hoping that if nothing else, I might use the experience as a springboard to another similar job.

After 2 months on the job, liking it very much, and having dozens of people tell how much happier I seemed, how much better I looked, I asked Mrs. Hawk, Vice-president in charge of Patient Services & long-time friend of mine, what the

cut off date was on my job. She said, "If you like the job, Jess, just hang in there. I think there's going to be good news for you. But I can't say anything concrete right now." About a week later the poor obese thing fell down in the hallway and broke her leg in 3 places, and had to have a surgical repair. She is near retirement age and may not return. So much for my ace-in-the-hole. So my job is now in it's 4th month. Nursing wants to make it permanent, administration says there's no money in the budget for it. I've been told that I'll be given a minimum of 30 days notice if they decide to terminate the position. So each day I know that I have at least 30 more days on the job.

Healthwise, I am presently doing better than I had dared hope. The herpes come and go frequently but aren't as severe as they once were. I've come to accept the sinusitis as chronic--it's been with me for more than 2 years now. I have night sweats 2 or 3 times a month varying from mild to drenching. I don't think that my stamina is what it once was, but I am able to jog 3 miles non-stop 3 or 4 times a week and I think that that is very important both physically and psychologically as an effective stress-reduction technique.

In August I came down ^{with} severe abdominal cramps and explosive diarrhea mixed with blood and mucus. It turned out to be shigellosis--source unknown. After two courses of antibiotics (the 2nd one double strength for 2 weeks) I am almost asymptomatic but my stools continue to test positive for shigella. My doctor thinks that I may now be a carrier of shigella and also thinks that that condition may be related to impaired immune response. If the next culture is positive, he is going to turn me over to an infectious disease specialist to see if anything else can be done. The possibility of being a carrier of shigella is particularly distressing because shigellosis is a reportable disease and precludes my ever working in direct patient care or in food handling. So, if I was still employed in the Emergency Room, I'd be on disability right now. Further, if my current position gets terminated, the available alternatives are significantly diminished.

Throughout all of this I have continued my volunteer work at the AIDS Project. Although it has been very difficult at times, I realize that it is one of the few stable things in my life. So it is good for my mental health. I think that if I gave that up, it would be an open admission of surrendering to my health problems. Then I would really be defeated. Secondly, it forces me to turn my attention away from my own petty concerns and get outside myself for a while.

Of course, Project work brings its sorrows as well as joys. Two men that I had worked with as a "buddy" for more than a year, died this summer within 10 days of each other. Of the two, I was closest to Ray and was with him daily during the final week, and all night during the last two nights. He let me "in" to share in that very special time of transition. And though it was a time of great sadness, it was peculiarly rewarding. I felt very privileged to have had the experience. I know that when my time comes, Ray will be there for me and my transition will be easier.

In late June, Steve Zimmerman (of Zimiz Hair Salon) succumbed to AIDS. It was a shock to me. I had seen him only two weeks before, hugged him and didn't even know he was ill. I think you also know Jerry Schmeitz. He used to operate the Neighborhood Outreach Program in Golden Hill when you and I were running the Gay Center. Jerry was diagnosed early this year and has had PCP, and neurological problems as his major ailments. He has recently started on AZT and we are all keeping our fingers crossed. Gary Rees and Patsy Healy and I were over to his place last night for a pot luck dinner--all high calory foods to try to put some

weight on him.

Also for the AIDS Project, I do "Safe Sex" lectures every other week, and one night each week I do a four-hour phone shift on the "AIDS Information Line". I don't plan to assume another "buddy" relationship until sometime next year. I think that it is very important to keep a certain amount of space between those relationships. I also assist in the training of new volunteers every couple of months. So I am not about to run out of things to do.

Sometime before the end of this month (now that Prop 64 is behind us) I expect to launch The Lesbian/Gay Archives of San Diego as an officially established organization. I think that it may become my most important endeavor. And I feel a sense of urgency about it now. The need is long overdue. The idea has been in the minds of many gay San Diegans for a long time. And I feel that if I don't get the ball rolling now, I may never do it. Another tiger by the tail. I know that if I want this to work it will have to be a life-time commitment.

This letter is beginning to look like a lifetime commitment. It really started out to be a brief note in response to your letter. But it has been therapeutic for me. This is the first time that I've put all of this down on paper and I think that I really needed to do that. I hope you don't mind that I chose you to dump on. I hope that you will feel honored because I have trusted you with some private information. Please treat it gently. I think that maybe your loss of Michael makes just little better equipped than most people to know what is going on with me.

Let me conclude on an up note. My overall mood is better than it has been for along time. So everything isn't perfect. But I am optimistic about the coming year. I feel stronger for having weathered the storms of 1986.

I hope that you will find time and be inclined to give me some feedback on all of this. I look forward to seeing you whenever that may be.

Love in the struggle,

Jess